

Mr Chairman & Members,

I'm Zachary Lassiter, Chairman of the Kalamazoo Regional Interagency Consumer Committee, a group of disability advocates and self advocates. Thank you for your time in this matter. I also want to thank our local Senator Tonya Schuitmaker for her ongoing efforts to improve the lives of people with various disabilities. With her history on the Van Buren County Community Mental Health Board, her history with the Elder Abuse Packages and her making herself available to meet with our group its clear she understands the need of those with various disabilities and we appreciate her ongoing efforts.

The Kalamazoo RICC is a group of disability self advocates with a diverse group of members in level of care needs, diagnosis, age, economic and ethnic background. While we have some service providers, disability advocates and family members as part of our group the majority of us are disability self advocates. I myself am on the Autism Spectrum with a diagnosis of Aspergers Syndrome. However a significant portion of our members are not on the Autism Spectrum.

One of our members is a parent who adopted a son who is on the Autism Spectrum. Her son is now thirteen years old and has not verbally communicated on word. Her husband works for an Intermediate School District in the special education department and their insurance, Blue Cross Blue Shield won't cover speech therapy. Yes, the insurance a special education employee carries wont even cover something needed by a special education student.

According to Harvard's School of Public Health the costs associated with taking care of a child on the Autism Spectrum can cost upwards of \$130,000 dollars a year. Applied-Behavioral Analysis can cost anywhere between \$30 and \$50 an hour, and based on the childs need can be anywhere between 20 and 40 hours a week. At \$40 an hour, 30 hours a week thats over \$50,000 a year. Relation Development Intervention (or RDI) can cost nearly \$50,000 a year alone. Floortime can cost anywhere between \$90 and \$200 an hour. As you can see the therapy costs of an Autistic Child alone can easily go well over \$50,000 a year.

Early intervention therapy for children on the Autism Spectrum is a crucial need. Peer reviewed research indicates various early intervention therapies can significantly improve the long term quality of life of those on the autism spectrum and can decrease the funds needed in the future for treatment. I myself am lucky enough to be able to sit here and speak to you, many of my peers however are not. I however do feel that if many of my peers were able to get early interventions needed they too would be able to sit here and communicate to you as well.

As a state with a struggling economy the economic impact of this bill is undeniable. It will bring many well educated people to the area with well paying jobs. These bills

The Kalamazoo RICC as a group have voted to support SB 414, SB 415 and SB 981, and ask that you vote in favor of this bill as well. Our support however does include significant concerns about these bills that we as disability self advocates want to make you aware of.

1. Our group of self advocates are very concerned about the loose wording of what is determined to be a treatment for Autism. These bills use terms such as "current protocols", and "evidence based". Who would define what the current protocols are? Who would define what is evidence based?

In the Autism Spectrum word alone a paper published by former Dr. Andrew Wakefield in the The Lancet in 1998 was not retracted until 12 years later in 2010 after it was determined that he literally made up numbers to support his claim that vaccines cause autism - however the damage was done and public trust in vaccines was lowered. Many parents then believed under the research of former Dr. Wakefield that metals caused Autism and sought chelation for their children - a very dangerous procedure that did result in deaths on the Autism Spectrum.

My point is I feel it should be better defined what treatments are the current protocols and evidence based in the law. I'm concerned that insurance companies can form their own determination on what is current protocol and what is not, thus making this legislation useless.

These are also groups are out there that prey on the hopes of parents being able to cure their children. These very active even holding large conferences every year to promote their miracle cures that actually have no benefit, and have resulted in the deaths of Autistic Children. One of these groups even pays former Dr. Wakefield to speak for them even though his research was retracted and him being barred from practicing medicine. With the current wording of these bills these groups who claim to be based on scientific evidence and define their own protocols could force insurance companies and tax payers to fund their miracle cures that have no benefit and risk the lives of Autistic Children.

2. We also feel the \$50,000 cap on yearly spending for treatment of children on the Autism Spectrum is too low for what is often needed for those who are of a higher level of need. As I said earlier the therapy related medical costs alone easily go over the \$50,000 cap alone.
3. We feel that the needs of those on the Autism spectrum after the age of 18 should be considered. Autism does not stop at the age of 18 and the long term care of those on the Autism Spectrum as well as the current adult population needs to be considered.
4. The Kalamazoo RICC is a group of people with diverse diagnosis's, and we feel that this bill heavily favors those on the Autism Spectrum verses other disabilities. The struggle for parents getting therapy and treatment is not unique to families and people affected by Autism Spectrum Disorders. We feel the bill should be more inclusive the whole spectrum of disabilities as well. This bill many of our members feel heavily favors one disability over another.

In future legislative sessions I hope you take into consideration the needs of people affected by all disabilities including those over the age of 18. However at this time we feel this is a great positive movement in the right direction.

I have also attached to my testimony the written testimony of Sarah Carmany a young lady on the Autism Spectrum and also Kalamazoo RICCs public policy chair whom Senator Schuitmaker has had the pleasure to meet earlier this month. She wanted to make it and testify today however she could not as she had class today. I hope that you take a few minutes to read through her thoughts on this matter as well before you make your decision on these bills.

Thank you for your time and consideration in this matter.

Zachary Lassiter, Chair  
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